

IN THE UNITED STATES DISTRICT COURT
FOR THE EASTERN DISTRICT OF PENNSYLVANIA

HASSAN SABREE, by his mother and next
friend, Hana Sabree; CATHERINE MEADE,
by her father and next friend, Robert A. Meade;
JOSEPH FRAZIER, by his mother and next
friend, Patricia Frazier, for themselves and
and all others similarly situated,

Plaintiffs,

v.

ESTELLE B. RICHMAN, in her official
capacity as Secretary of the Department of Public
Welfare of the Commonwealth of Pennsylvania,

Defendant.

Civil Action No. 02-CV-3426

Class Action

FIRST AMENDED COMPLAINT

I. Introduction

1. Plaintiffs and the class members they seek to represent are persons with mental retardation who reside with family members or other caregivers who are increasingly unable to provide them with the support they need. Plaintiffs and class members need residential mental retardation services, such as in intermediate care facilities for persons with mental retardation (ICFs/MR) funded under Defendant's Medical Assistance program.

2. Under Title XIX of the Social Security Act, Plaintiffs and class members have an enforceable entitlement to appropriate ICF/MR services and to have access to those services with reasonable promptness. Despite their need and eligibility for ICF/MR services, Defendant has placed Plaintiffs and class members on lengthy waiting lists for services and has implemented policies and practices that impede access to those services. As a result of their

inability to access necessary and appropriate ICF/MR services, Plaintiffs and class members are increasingly at risk of injury, institutionalization, and regression.

3. Defendant's actions violate Plaintiffs' and class members rights under Title XIX of the Social Security Act and 42 U.S.C. § 1983. Plaintiffs and class members seek declaratory and injunctive relief.

II. Jurisdiction and Venue

4. This Court has jurisdiction over this action pursuant to 28 U.S.C. § 1331 and 1343.

5. Plaintiffs' claims are authorized by 42 U.S.C. §§ 1396 and 1983 and 28 U.S.C. §§ 2201 and 2202.

6. Venue is appropriate in this district pursuant to 28 U.S.C. § 1391(b)(2) since a substantial part of the events that give rise to this Complaint occurred in this district.

III. Parties

7. Plaintiff Hassan Sabree is a 25-year-old man with who resides in Philadelphia, Pennsylvania. Mr. Sabree has Down Syndrome, resulting in a moderate mental retardation, as well as mild hearing loss and severe psoriasis. Mr. Sabree brings this action through his mother and next-friend, Hana Sabree.

8. Plaintiff Joseph Frazier is a 26-year-old man who resides in Philadelphia, Pennsylvania. Mr. Frazier has moderate mental retardation and autistic tendencies. Mr. Frazier brings this action through his mother and next-friend, Patricia Frazier.

9. Plaintiff Catherine Meade is a 33-year-old woman who resides in Montgomery County, Pennsylvania. Ms. Meade has mental retardation. She brings this action through her father and next-friend, Robert A. Meade.

10. Defendant, Estelle B. Richman, is the Secretary of Public Welfare of the Commonwealth of Pennsylvania. Defendant Richman administers the Department of Public Welfare (DPW), which is the single state agency with responsibility to implement Pennsylvania's Medical Assistance Program. 42 U.S.C. § 1396a(a)(5); 55 Pa. Code § 101.1(e). Defendant Richman is responsible to assure that Pennsylvania's Medical Assistance program is operated in compliance with federal law. Defendant Richman is sued in her official capacity only for actions and omissions under color of state law.

IV. Class Action Allegations

11. Plaintiffs bring this action on their own behalf and on behalf of a class composed of all Pennsylvania Medical Assistance recipients who are eligible for ICF/MR services, are on the waiting list for residential services, and not provided with appropriate ICF/MR services.

12. The action satisfies the prerequisites of Federal Rule of Civil Procedure 23(a):

a. The size of the class is so numerous as to make joinder of all class members impracticable.

(1) Based on a 1999 analysis by DPW, there were 3,297 Pennsylvanians with mental retardation on its waiting list (or on a "shadow" waiting list) who were determined to have "emergency" needs (i.e., needing services immediately) or "critical"

needs (i.e., needing services within one year). Approximately 1,146 (29%) of those individuals were determined to need residential services with 24-hour staffing. An April 2001 analysis by DPW suggested that there were approximately 8,310 persons on the waiting list with emergency or critical needs. Assuming that, as in the earlier DPW study, about 29% of those individuals need residential services with 24-hour staffing, there are approximately 2,409 Pennsylvanians who need that level of service. These individuals would be eligible for ICF/MR services, are on the waiting list, and are not being provided with ICF/MR services.

(2) Factors in addition to class size exacerbate the impracticability of joinder. Class members are geographically dispersed throughout Pennsylvania, and they are unlikely to have the resources to pursue litigation.

b. There are questions of fact and law common to all class members, including, but not limited to: (1) whether Defendant's policies and practices impede the development of and class members' access to ICF/MR services; (2) whether Defendant's policies and practices violate class members' entitlement to receive appropriate ICF/MR services; and (3) whether Defendant's policies and practices violate class members' entitlement to receive appropriate ICF/MR services with reasonable promptness.

c. Plaintiffs' claims are typical of the claims of class members.

d. Plaintiffs will fairly and adequately protect the interests of class members. Plaintiffs have no interests adverse to or in conflict with those of class members. Plaintiffs' counsel have extensive experience in civil rights, disability, class action, and Medical Assistance litigation.

13. This action can proceed as a class pursuant to Federal Rule of Civil Procedure 23(b)(2). Defendant has acted or refused to act on grounds generally applicable to all members of the class, making final declaratory and injunctive relief appropriate with respect to the class as a whole.

V. Facts

A. Plaintiffs' Service Needs

14. Plaintiff Joseph Frazier is a 26-year-old man with moderate mental retardation and autistic tendencies.

15. Mr. Frazier is eligible for and receives Medical Assistance benefits.

16. Because of his mental retardation, Mr. Frazier requires supervision at all times. He cannot be left alone for even brief periods of time without risk to his personal safety. If unattended, he would leave the house and wander into the street with no awareness of the danger of being hit by an automobile. He has injured himself on the stove; he does not know what to do in the event of a fire or other emergency; he would readily open the door to a stranger. Mr. Frazier cannot independently attend to many activities of daily living. He cannot shop or prepare meals without supervision, he cannot manage his own money, and he cannot independently use public transportation.

17. Mr. Frazier currently resides with his mother, Patricia Frazier, and his 79-year-old grandmother in the family home.

18. Mr. Frazier's mother works full time. Until October 2004, Mr. Frazier's grandmother was his primary caregiver during the day when his mother worked.

19. Between his graduation from high school and April 2004, Mr. Frazier had no regular program of mental retardation services. He sat at home all day doing nothing but listening to the radio. His skills regressed and he showed increased frustration and maladaptive behaviors, making it difficult for his mother to take him out in public.

20. In April 2004, after this lawsuit was filed, Mr. Frazier was provided with a day program two days per week. In October 2004, his day program was expanded to five days per week. While this day program offers him socialization opportunities and has resulted in some behavioral improvements, it does not provide him with the type and level of habilitation services he needs to maintain and improve his life skills.

21. Mr. Frazier needs a comprehensive mental retardation program to maintain and improve his life skills. Three years ago, the County Office of Mental Retardation classified Mr. Frazier as having an "emergency" (*i.e.*, immediate) need for services.

22. Mr. Frazier is eligible for and his needs can be appropriately met with ICF/MR services in the community.

23. Mr. Frazier's mother requested residential services, including ICF/MR services, for him. She was told that he would be placed on the waiting list. He remains on the waiting list for residential services and has never been offered any residential services.

24. Plaintiff Catherine Meade is a 33-year-old woman with moderate mental retardation and some mental health issues.

25. Ms. Meade is eligible for and receives Medical Assistance benefits.

26. Because of her mental retardation, Ms. Meade requires supervision at all times. She cannot be left alone for even brief periods of time without risk to her personal

safety. She does not know what to do in the event of a fire or other emergency and would readily open the door to a stranger. Ms. Meade cannot independently attend to many activities of daily living. She cannot shop or prepare meals without supervision, she cannot manage her own money, and she cannot independently use public transportation.

27. Ms. Meade currently resides with her parents, Robert A. and Karen Meade, in the family home.

28. Mr. Meade, age 62, has primary caregiving responsibilities for his daughter. Approximately a decade ago, Mr. Meade arranged to work from his home so as to have a sufficiently flexible work schedule to meet his daughter's significant needs. This substantially reduced his income and job opportunities. Until a few years ago, Mrs. Meade worked full-time outside the home and currently works full-time from the home.

29. Ms. Meade receives limited mental retardation services, which are inadequate to meet her needs. Between June 2001 and January 2002, Ms. Meade was provided with fewer than three hours of week of services in a pre-employment program. Beginning in January 2002, Ms. Meade began to receive supported employment services for two days per week, four hours per day, and she attended a mental health program two days a week for five and one-half hours per day. She no longer attends either of those programs. Now, Ms. Meade attends a workshop program five days a week for six and one-half hours a day. This is not adequate to meet her need for habilitation services.

30. Ms. Meade needs a comprehensive mental retardation program to maintain and improve her life skills. She needs greater opportunity for interaction with her peers and for

activities that would provide stimulation. Ms. Meade has a strong desire to move into a residential program with her peers and to become as independent as possible.

31. Ms. Meade is eligible for and her needs can be appropriately met with ICF/MR services in the community.

32. Ms. Meade's parents repeatedly have requested residential services, including ICF/MR services, for their daughter. In December 1999, the Montgomery County Office of Mental Retardation determined that Ms. Meade was in "critical" need of services.

33. The Montgomery County Office of Mental Retardation has directed Ms. Meade's family to three ICFs/MR since this case was initiated. One was a congregate, segregated facility which was inappropriate to meet Ms. Meade's needs. Another program was inappropriate because it had a cat, and Ms. Meade is allergic to cats. The third program included a number of non-verbal residents and was inappropriate given Ms. Meade's desire for social companionship. Ms. Meade remains on the waiting list for residential services.

34. Plaintiff Hassan Sabree is a 25-year-old man with Down Syndrome, which results in moderate mental retardation. Mr. Sabree also has a mild hearing loss and severe psoriasis.

35. Mr. Sabree is eligible for and receives Medical Assistance benefits.

36. Because of his mental retardation, Mr. Sabree requires supervision at all times. He cannot be left alone for even brief periods of time without risk to his personal safety. Mr. Sabree cannot independently attend to many activities of daily living. He cannot shop or prepare meals without supervision, cannot meet his hygiene needs, cannot apply his psoriasis medication, and cannot manage his own money.

37. Mr. Sabree currently resides with his mother, Hana Sabree, in the family home.

38. Ms. Sabree, who holds a full-time job, is her son's sole caregiver. Ms. Sabree provides for her son's daily care, including cooking, cleaning, laundry, shopping, assisting him with his hygiene, and assisting him with the extensive daily application of medication required to treat his psoriasis.

39. Ms. Sabree finds it increasingly difficult to meet the demands of her full-time job and the demands of caring for her son.

40. Between his graduation from high school in the spring of 2001 and July 2003, Mr. Sabree had no mental retardation services. He stayed alone at home all day while his mother was at work, which caused his skills to regress. In July 2003, Mr. Sabree was approved to receive day services five days a week. These services afford him socialization, but do not provide the level of habilitation services he needs to maintain and improve his life skills.

41. Mr. Sabree needs a comprehensive mental retardation program to maintain and improve his life skills.

42. Mr. Sabree is eligible for and his needs can be appropriately met with ICF/MR services in the community.

43. Mr. Sabree's mother requested residential services for him prior to his graduation from high school and again in April 2002. She was told that he would be placed on the waiting list and that it would be months or years before Mr. Sabree received residential services. He remains on the waiting list for residential services.

B. Pennsylvania's Mental Retardation System

44. In Pennsylvania, provision of mental retardation services is governed by the Mental Health and Mental Retardation Act of 1966 (MH/MR Act), 50 Pa. Cons. Stat. Ann. §§ 4101-4704.

45. Under the MH/MR Act, DPW must assure that Pennsylvanians with mental retardation receive adequate services. 50 Pa. Cons. Stat. Ann. § 4201(1).

46. DPW's mental retardation policy is based on the principle of "normalization." This principle seeks to assure the individual's right "to live a life which is as close as possible in all aspects to the life which any member of the community might choose. For an individual with mental retardation who requires a residential service, the design of the service shall be made with the individual's unique needs in mind so that the service will facilitate the person's ongoing growth and development." 55 Pa. Code § 6400.1.

47. For many years, County Offices of Mental Retardation (OMRs) have been unable to provide mental retardation services, including community residential services, to all persons who seek such services and are eligible. The County OMRs have developed waiting lists for these services. DPW is aware of these waiting lists and the need to expand services. As of April 2001, DPW was aware that there were approximately 2,400 persons with mental retardation with "emergency" or "critical" need for residential services.

C. The Medical Assistance Program and ICF/MR Services

48. The Medical Assistance program, authorized by Title XIX of the Social Security Act, 42 U.S.C. § 1396 *et seq.*, is a joint federal-state program. Under Title XIX, the federal government reimburses states for a portion of the expenditures which they incur to

furnish Medical Assistance to individuals whose income and resources are insufficient to cover the costs of their medical care.

49. States are not required to participate in the Medical Assistance program. If they choose to do so, however, they must adopt State Plans that delineate the standards for determining eligibility and the extent of Medical Assistance benefits and they must comply with the federal statute and implementing regulations. Pennsylvania has chosen to participate in the Medical Assistance program and has adopted a state plan.

50. Title XIX mandates that a State Plan provide certain specified health care services. 42 U.S.C. § 1396a(a)(10)(A)(i) (incorporating 42 U.S.C. §§ 1396d(a)(1)-(5), (17), (21)). These mandatory services include, *inter alia*, inpatient hospital services, outpatient services, nursing facility services, and physician services.

51. Title XIX permits (but does not require) a State Plan to provide other specified Medical Assistance services delineated in 42 U.S.C. § 1396d(a). *See* 42 U.S.C. § 1396a(a)(10)(A). If a states chooses to provide an optional service, it must provide those services to all eligible persons who need them.

52. ICF/MR services are an optional service under Title XIX. 42 U.S.C. § 1396a(a)(10)(A); 1396d(a)(15). Pennsylvania has chosen to provide ICF/MR services in its State Plan. As such, Medical Assistance recipients who are eligible for ICF/MR services have an entitlement to receive those services.

53. Pennsylvania benefits from its inclusion of ICF/MR services in its state plan because more than fifty percent of the costs of those services are covered by federal funds.

54. The primary purpose of ICF/MR services is to provide health and habilitation services for individuals with mental retardation or other developmental disabilities. 42 U.S.C. § 1396d(d).

55. The key component of ICF/MR services is "active treatment." Federal law requires that ICF/MR residents "receive a continuous active treatment program that includes aggressive, consistent implementation of a program of specialized and generic training, treatment, health services, and related services" 42 C.F.R. § 483.440(a)(1). Active treatment "is directed toward -- (i) the acquisition of the behaviors necessary for the client to function with as much self-determination and independence as possible; and (ii) the prevention or deceleration of regression or loss of current optimal functional status." *Id.*

56. An ICF/MR must develop an individual program plan (IPP) for each resident as part of its active treatment obligation. 42 C.F.R. § 483.440(c)(6). The IPP must identify the interventions to support the resident toward independence, include when necessary: training in basic personal care skills needed for independence and privacy such as personal and dental hygiene, self-feeding, dressing, grooming, and communication skills. *Id.*

57. A person eligible for Medical Assistance must meet three criteria to be eligible for ICF/MR services in Pennsylvania. First, the person must have a diagnosis of mental retardation. Second, the person must need active treatment. Third, the person's physician must recommend that he or she needs the level of care provided in an ICF/MR. 55 Pa. Code § 1181.53(b)(4).

58. The need for active treatment is satisfied if "the person will benefit from a professionally developed and supervised program of activities, experiences or therapies that

are necessary for assisting the individual to function at his/her greatest physical, intellectual, social or vocational level." DPW, *Mental Retardation Bulletin # 00-02-13* (Aug. 7, 2002).

59. Before an individual can be admitted to an ICF/MR, the ICF/MR must conduct an evaluation to determine "if the facility can provide for the client's needs and if the client is likely to benefit from placement in the facility." 42 C.F.R. § 483.440(b)(3).

60. In Pennsylvania, ICF/MR services are provided through several types of programs. DPW directly operates six congregate, segregated ICFs/MR. In addition, DPW funds approximately 200 privately-operated ICFs/MR. Some of those privately-operated facilities are large and segregated while others are small, integrated community-based programs in residential homes.

61. Under the MH/MR Act, the County OMRs serve as the point of entry into Pennsylvania's mental retardation system for persons who want to apply for services. 55 Pa. Code § 6201.13(a). Persons seeking ICF/MR services must do so through their County OMR. All referrals to one of Pennsylvania's ICFs/MR must be approved by the County OMR. 55 Pa. Code § 6000.821(a)(2).

62. Most individuals with mental retardation and their families who seek services are not aware that they must specifically request ICF/MR services, rather than other types of residential services. They simply inform their County OMRs that they want and need residential services. The County OMRs make no effort to specifically ask whether they want to be directed to ICFs/MR. Instead, County OMRs simply place persons requesting residential services on the waiting list.

63. DPW has significant control over the development and provision of ICF/MR services.

64. DPW adopted a policy in 1996 that states that it "does not currently support the development of new ICF/MR proposals." 55 Pa. Code § 6000.821(b). As a result of this policy, which remains in effect, DPW has authorized the development of only a small number of new ICFs/MR.

65. DPW's policy concedes that the appropriate ICF/MR setting for persons with mental retardation are small (four-person) programs in residential settings that are integrated into residential neighborhoods so as "to foster social integration and participation with neighbors in the general population." 55 Pa. Code § 6000.821(b)(1).

66. DPW has been and continues to be aware of a substantial waiting list for residential services for persons with mental retardation who are entitled to ICF/MR services.

67. Plaintiffs and class members need residential mental retardation services and are eligible for ICF/MR services.

68. As DPW's policy acknowledges, it is appropriate to provide Plaintiffs and class members with ICF/MR services in small, integrated, residential settings.

69. There are not a sufficient number of appropriate ICF/MR placements available to meet the needs of Plaintiffs and class members, resulting in their placement on the waiting list.

D. Irreparable Harm

70. Plaintiffs and class members have and will continue to suffer irreparable harm absent injunctive relief. They have no adequate remedy at all.

VI. Claims

A. Count I -- Entitlement to ICF/MR Services

71. Paragraphs 1 through 70 are incorporated by reference.

72. Under Title XIX, states that participate in the Medical Assistance program must make Medical Assistance benefits available to eligible persons. 42 U.S.C. § 1396a(a)(10)(A). Medical Assistance benefits include, at the option of the state, ICF/MR services. 42 U.S.C. § 1396d(a)(15).

73. Pennsylvania participates in the Medical Assistance program and has chosen in its State Plan to cover ICF/MR services as a benefit for eligible persons.

74. Plaintiffs and class members are eligible for Medical Assistance benefits and meet the eligibility criteria for ICF/MR services. Plaintiffs and class members, therefore, are entitled to receive ICF/MR services under Defendant's Medical Assistance program.

75. Defendant's policies and practices have impeded the development of appropriate ICF/MR services, exacerbating the lengthy waiting list for residential mental retardation services. There are an inadequate number of appropriate ICFs/MR to meet the needs of Plaintiffs and class members.

76. Defendant has failed to assure that Plaintiffs and class members have access to appropriate ICF/MR services.

77. Defendant's acts and omissions under color of state law violate 42 U.S.C. § 1396a(a)(10)(A) (incorporating 42 U.S.C. § 1396d(a)(15)) and 42 U.S.C. § 1983.

B. Count II -- Failure to Assure ICF/MR Services with Reasonable Promptness

78. Paragraphs 1 through 77 are incorporated by reference.

79. Title XIX mandates that Medical Assistance "shall be furnished with reasonable promptness to all eligible individuals." 42 U.S.C. § 1396a(a)(8). Defendant must furnish Medical Assistance, including ICF/MR services, promptly and without any delay caused by the agency's administrative procedures. 42 C.F.R. § 435.930(a).

80. Plaintiffs and class members have requested and are entitled to appropriate ICF/MR services.

81. Plaintiffs and class members have been placed on lengthy waiting lists for community residential services.

82. Defendant's policies and practices have delayed access to ICF/MR appropriate services for Plaintiffs and class members.

83. Defendant has failed to assure that Plaintiffs and class members are furnished with ICF/MR services with reasonable promptness.

84. Defendant's acts and omissions under color of state law violate 42 U.S.C. §§ 1396a(a)(8) and 1983.

VII. Request for Relief

85. Plaintiffs respectfully request that the Court:

- a. retain jurisdiction over this action;
- b. declare that Defendant's actions and inactions violate Title XIX of the Social Security Act;

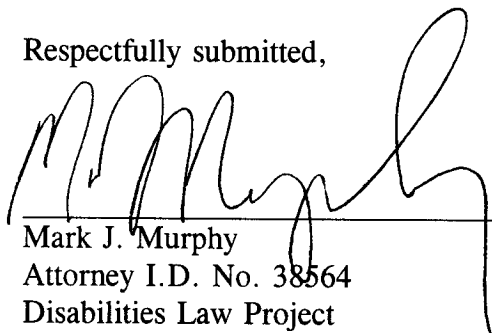
c. issue appropriate classwide injunctive relief to enjoin Defendant from continuing to violate Title XIX and to take appropriate steps to remedy their violations and assure that Plaintiffs and class members have access to appropriate ICF/MR services with reasonable promptness;

d. issue such other relief as may be just, equitable, and appropriate, including an award of reasonable attorneys' fees and costs pursuant to 42 U.S.C. § 1988.

Respectfully submitted,


Dated: November 29, 2004

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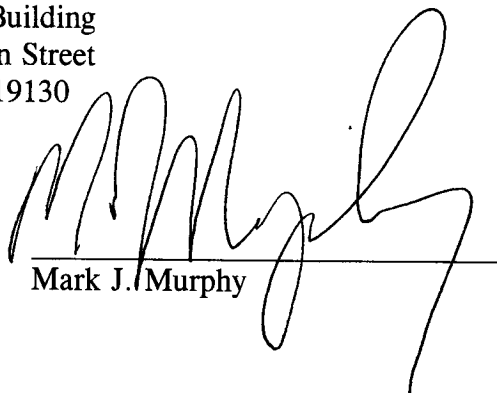
Attorneys for Plaintiffs

CERTIFICATE OF SERVICE

I, Mark J. Murphy, hereby certify that true and correct copies of the foregoing First Amended Complaint were served on the following by first-class mail, postage prepaid on this 29th day of November, 2004:

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